ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

July 1993

Preparing For Death or Giving Up Hope?

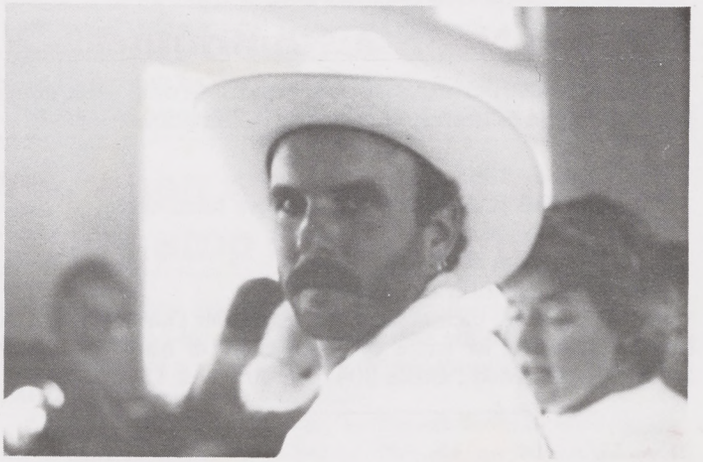
By Sean Kinney

[Editor's Note: Sean Kinney is a member of MCC in the Valley in North Hollywood, CA. He is one of the most respected activists in the Los Angeles community of persons living with HIV/AIDS. This article originally appeared in the June, 1993 newsletter of "Being Alive," a people with HIV/AIDS action coalition.]

In the last several months, I have embarked on a journey through an undiscovered forest of complicated decisions. For years I knew this was coming. With no haste now, tomorrow is here. In what I consider a very short period of time (six months to be exact), I am flooded with decisions on treatments that affect the balance of my life.

How often I have heard and read about how one day this time would come. My perspective they said "would change..."; it has. With great frequency I have been sharing the latest test results and speculations offered to me from Dr. Glen Mathisen in collaboration with the other brilliant HIV professionals at Olive View Medical Center. I strive to hold nothing back each time I tell my story. Friends, family, and associates have heard it all, the truth through the heavy veil of reality.

We have two choices in this disease. We either prepare ourselves for the inevitability of AIDS or we fight the process each and every day, every hour. I think it is fair to say, that in very broad terms, the thousands of people with HIV in my life share one of these two philosophies. For years I based my decisions on the second philosophy. Without notice I am moving towards the former.



Mr. Sean Kinney

Already I hear you saying phrases like "giving up," "bringing it on," "not very aggressive." Perhaps. But when do we just say enough, and live with what God is offering? Since we have no clue what comes after this, why is it not OK to run towards it? Listen, you do not have to be around this once 6'3", 225 pound man long, not to know that things are continuously changing. I find myself right in the middle of watching people's lives change as they watch my downward spiral. It

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Rev. Ken South To Speak At AIDS Luncheon

The UFMCC AIDS Ministry is pleased to announce that the Rev. Ken South will be the featured speaker at the UFMCC AIDS Ministry Luncheon at General Conference XVI in Phoenix, AZ. Rev. South, an ordained minister with the United Church of Christ, is the Executive Director of the U.S.'s AIDS National Interfaith Network (ANIN). Prior to assuming his current position, he worked as the Executive Director of Aid Atlanta.

Rev. South recently returned from the International Conference on HIV/AIDS, held in June in Berlin, Germany. He was one of four speakers in a roundtable on religious issues and AIDS. Two hundred people attended this event, the first of its kind at an International Conference on AIDS. While there was a lot of "church-bashing" from the audience, Rev. South said the panel was an educational experience for him. One of his co-presenters was an Anglican lay woman working in Central Africa. She challenged the church to get "out of the vicarage, and onto the frontlines" of the epidemic. Rev. South also discovered that ANIN is the only organization of its kind in the world.

ANIN had a booth at the International Conference, where pamphlets, including "Spiritual Strength for Survival" and other UFMCC resources were quickly picked up by many of the 14,000 participants. ANIN was given a prime location right at to top of the escalators. "Everyone had to look at our banner as they rode up the escalator!" South gleefully reported.

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"AIDS, Medicine, and Miracles" Conference Goes Bi-Coastal

The Sixth Annual "AIDS, Medicine, and Miracles" Conference becomes two conferences this year. Previously held as one conference in Boulder, Colorado over the last five years, this year (due to the Colorado boycott), one conference will be held at the University of California at Berkeley, and the other will be held at the Omega Institute at Rhinebeck, New York. The Berkeley conference will be held July 8-11, and the New York conference will be held September 23-26.

Speakers for the Berkeley conference include Ram Dass, Rev. Scott Allen, Martin Delaney, Sally Fisher, and Paul Volberding, M.D. Speakers for the New York conference include Niro Asistent, Martin Delaney, Sally Fisher, Richard Elion, M.D., and Ysaye Barnwell.

The conference is billed as "a wonderful retreat, a time for learning, play, tears, inspiration, and joy. The conference is a forum for an array of expert opinion and for the wisdom of people living with HIV. There is a balance of presentations, workshops, and creative experiences ranging from medicine to music."

Workshop themes include: Grief, Medical Update, Laughter in Healing, Women's Treatment Issues, Death and Dying, HIV and Exercise, Sexuality and Intimacy, Psychoneuroimmunology, Spirituality in Healing, Meditation, Nutrition and HIV, Chinese Medicine, and Attitudinal Healing.

For Conference Registration fees and further information, contact AIDS, Medicine, and Miracles, P.O. Box 9130, Maxwell Building, 311 Mapleton, Boulder, CO 80301-9130. ▼

Special Request: We Need A Computer!

The UFMCC AIDS Ministry needs an IBM-compatible computer with the following minimum specifications:

386 or 486;
4 MGB RAM, 100 mgb or more hard-drive;
VGA or Super VGA monitor;
Windows software.

Also a laser printer is needed.

If you can help, please contact Rev. Elder Don Eastman at (213) 464-5100, or write to UFMCC AIDS Ministry, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA 90029. ▼

Rev. Ken South

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Rev. South also noted a breakthrough on the religious front: the International Christian AIDS Network (ICAN) held its first official function. Founded at last year's International Conference in Amsterdam, there was much debate this year over including non-Christian religions in the network. At this point, ICAN will remain solely Christian.

South attended a number of workshops focusing on the Concorde study, which has received a great deal of press. South told ALERT, "Everybody came away with the results they wanted to hear. Everything is up in the air. No one knows what to do now for treatment, and so everybody is taking their own paths."

Rev. South was also overwhelmed with the problems of countries where tens of thousands of people are diagnosed with HIV, and yet these countries' entire budget for AIDS is only in thousands of dollars. "Discussions about combination treatments, stimulating the immune response, and slowing down the virus, pale when confronted with the fact that people can't even get clean water in some of these countries," he said.

At the AIDS Ministry Luncheon, Rev. South will be drawing on his experiences in Berlin as well as his knowledge of the AIDS Interfaith effort. He will be speaking specifically about UFMCC's unique position and role in the HIV/AIDS pandemic.

The UFMCC AIDS Ministry Luncheon will be held Friday, July 23. This is a ticketed event, and tickets must be purchased by Wednesday, July 21 at noon. The ticket price is $20. ▼

Vaccine Trials For HIV-Positive Children and Pregnant Women

The National Institute of Allergy and Infectious Diseases has begun the first clinical trials of therapeutic AIDS vaccine candidates in pregnant women who are HIV-infected but otherwise healthy.

In separate Phase I trials, two experimental vaccines are being evaluated primarily for safety but also for their potential to stimulate anti-HIV immune responses in expectant mothers and to prevent their passing HIV infection to their babies.

Although testing different candidate HIV vaccines, the trials are designed similarly. Both enroll women between ages 16 and 40 who are free of AIDS-defining symptoms and have 400 or more CD4+ T cells, a primary cell of the immune system. Volunteers must not have any other medical conditions that would make their pregnancy high-risk. Therapy with AZT can be continued during the trial.

The trials are being conducted through two of NIAID's national clinical trials networks, the AIDS Vaccine Evaluation Group and the AIDS Clinical Trials Group.

One trial, known as AVEG 104/ACTG 235, will be conducted at seven sites located in Rochester, Seattle, St. Louis (two sites), Nashville, Baltimore, and San Francisco. The second trial, known as AVEG 102/ACTG 234, will be carried out at one site in New Haven.

In addition, the U.S. National Institutes of Health has announced the first trial of an HIV treatment vaccine for children. The study needs children between the age of one month and 12 years, and must have "well-documented HIV infection...but no symptoms of HIV disease."

The trial will be conducted at 12 sites, with 90 children in the program. For more information about the trial sites or eligibility criteria for any of these trials, call the AIDS Clinical Trials Information Service, 1-800-TRIALS-A, from 9 a.m. to 7 p.m., ET weekdays. Spanish-speaking information specialists are available. ▼

Preparing for Death...

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is those I love that will remember this journey. If I can be honest with AIDS in my body, they can accept the emotional struggles.

Let's talk about hope for just a minute. Hope has been given a bad rap. We are only taught through the words and actions of others that hope is for good things to come. Today I hope for understanding, for the will to accept, for the support of so many, and yes, for the success of the thousands of men and women who will one day trip upon the final solution to this damn mess.

I am today thoroughly challenged by this process. For years I have heard the stories. Each time a new story was told, the sounds of the words just circled around in my super-collider head. You see, I have lived through others, the events of my life today. I am not shocked; I am disappointed, not angry. My dear friend Richard Porter clued me in to a beautifully strong image; Lady Liberty of Justice holds hope and acceptance on her perfectly balanced scale. Since my release from the hospital following a bout of pneumocystis, this image has ruled my life.

attention. It is because of all those who went before me that I can with good conscious declare the end is about compassionate listening and intimate knowledge, shared freely.

There is a satisfaction of doing AIDS with an audience. Since I have spoken HIV in almost every breath for the last six years, my experience is broadened by those leaders I once joined around the table. Their experience with me is not testimony at a planning council meeting, rather it is the impact of these endless decisions on a life they know with their heart. It is still important to have AIDS publicly. I serve as a reminder of our war and why we are determined to battle on. Each day I am alive someone new sees a man with AIDS. Each day another ear is filled with the realities of AIDS in my body. Each day a victory is shared in my office when I make it through another day without a seizure. Each day encourages my hope for tomorrow.

And so it is quite OK for me to say I am preparing for death. I say it to you; I have said it for weeks to those who would listen. I as strongly say, as one human can say to another, I am not giving up, and I am certainly not bringing death on any faster! My lovely friend Rick Noll and I share an expression that must be done *a' la* Bette Davis, "Dead! You Know." This has become the theme of a very special process we do

"What power we bring to our lives, when we just look around and accept what we have and never stop looking ahead!"

I see myself coming to terms with the thought that should today bring the cure, for me it will be too late. There seems no returning from the point where I am now. A better decision seems to be acceptance, while I hope for tomorrow. What power we bring to our lives, when we just look around and accept what we have and never stop looking ahead! In front of me lies the challenge: behind me is yet another experience: walk on forward.

As a Christian, I have always enjoyed the Lent into Easter season. Of course, Christmas held my interest as a child, but after eight years of AIDS, it is Lent where I get my strength. Perhaps like no other image, alive, dead, or otherwise, seeing the Christ in the Garden of Gethsemane gives me the desire to move along. There amidst the olive trees, he kneels supporting his face with his hands. He knew his future and it was death. His conviction embraced real acceptance, while the tears from his heart moistened the ground below through his calm fingers. The dilemma is that when it is my time to go, why it is OK for Christ to accept God's will and not me?

You see, the image in front of me isn't going away. I have watched the images of AIDS from way back when it was called GRID. How much more real does it get? My disease, of course, is different just because it is mine. But, you know, my intuition says: relax, observe and pray, your head is in the right place. I see now for how many years I have been preparing the way for this part of my life. When close friends and comrades died, I sought the same intimacy with others just so that when this time came in my life, I could live completely dependent on everyone in my life, while not interrupting their lives in the process.

Amidst committee meetings, board meetings, speeches and protests, I have been steadily preparing. My knowledge comes from our community. I am humbled that my understanding of AIDS has been in this way. I have the opportunity to stay clear on the issues, since it is my life these issues encompass. For as long as I have the energy, AIDS has my with each other. Rick prepares me for leaving and I prepare him for when I let go. The expression somehow reminds us with humor of a vital part of our relationship together, as I battle this disease we call AIDS.

After two years, in January I stepped down as President of the Board of Directors of Being Alive, People with HIV/AIDS Action Coalition in Los Angeles. The day I accepted the difference between abilities and capabilities is the day I said "let go." I have for years watched close comrades and friends lose their cognitive abilities. In our relationship, anger and paranoia replaced kindness and support during their end-stages. Where once I could count on their unique insights and visions, now frustration, sympathy and fear came to control our alliance. To back away with grace and dignity ensures compassion from others. My brain struggles to control this body while losing ground day-by-day. Before I have an opportunity to create havoc in the lives of those who support me, I felt it best to become an observer and not the leader.

Preparing for the future meant moving away from the constancy of decisions and responsibility. I saw in the mirror the image of a warrior ready to retire. The image on my face, drawn, pasty, flaky, is strong with familiarity in your heart. You have seen this before, now your image takes its rightful place among the others. Yes, it is still to be loved by you and so many others.

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ALERT

ALERT is a monthly newsletter containing information on AIDS Legislation, Education, Research and Treatment. The Editor is Rev. Dr. A. Stephen Pieters. For more information, or to send a donation, please write or call: ALERT, c/o UFMCC, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA 90029; (213) 464-5100.

Preparing for Death...

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Acceptance comes in many packages. While I find myself armed to tackle certain decisions, the real emotions that arise once the decision is acted upon are overwhelming. There have been so many varied opinions on correct HIV therapy. Now that I am at this point, it is hard not to look back towards treatment decisions I made years ago. "Perhaps I should have...," or "If only I had..." haunt my sanity. When the focus becomes the future, these somehow fade away. They will not affect tomorrow; they are energy spent. What we experience from this point forward should rule supreme. I am going through this one time. May I just say, what a journey.

Today I am a man with AIDS experiencing the inevitability of eight years of infection. Where once I organized my life around meetings, today I rely on second hand accounts. I push to irregularly attend meetings. Today I am seeking a new relationship with Being Alive. When my predecessor stepped down just over two years ago, his health quickly changed his participation, and this allowed for a strong transition. Congratulations, Walt, your time and place have come. Go with God. Amid today's acceptance lies tomorrow's challenges. There has come a time in my AIDS journey, when the time between serious decisions becomes a snap. From appointment to appointment there is always something to ponder through the tears. We are not alone until we have to make the decision. We must consider it all; the stakes are very high. There seems to always be costs..."what now?"

Shall we be challenged in moving together on our death while we live this process of life? I wish to have the grace to understand my situation each and every step forward until I begin to finally let go. We leave before you think... I just know. ▼

[The following articles are reprinted with permission from "Treatment Issues," Volume 7, Number 5, the Gay Men's Health Crisis Newsletter of Experimental AIDS Therapies.]

Foscarnet/Ganciclovir Combo For CMV

The combination of ganciclovir and foscarnet, both approved to treat CMV retinitis as monotherapies, may be effective in persons with AIDS who have failed both drugs. In a study reported in The Journal of Infectious Diseases (May 1993:1184-8), ten patients with CMV were given a combination of ganciclovir and foscarnet at standard doses. Nine of the ten responded to therapy. Compared to those treated with foscarnet or ganciclovir alone, the patients on combination treatment had a higher rate of anemia (a reduced level of red blood cells). No other significant differences between monotherapy regiments and the combination were noted. A larger study examining combination ganciclovir/foscarnet was just initiated by the U.S. Federal Government's National Eye Institute. Accrual has just started; results are expected in a couple of years. ▼

Gynecological Care Manual For HIV-Positive Women

Risa Denenberg, an AIDS activist and family nurse practitioner, has written "Gynecological Care Manual for HIV-Positive Women." The 173-page manual is designed to help primary care providers offer appropriate gynecological services to HIV-positive women. The manual features sections on General Information, Setting Up GYN Services, GYN Findings in HIV Infection, GYN Screening for HIV-Positive Women, Protocols for Gynecological Infections, and Resources. Call 800-225-0694 or fax 405-924-9414 to order copies or for more information. ▼

New British Study Results: Smoking Is Still Bad For You

Two reports provide new evidence that smoking accelerates progression to AIDS in HIV-positive individuals. A British study reported in AIDS (May 1993:705-710) compared 43 HIV-positive smokers (at least ten cigarettes per day) with 41 HIV-positive non-smokers. The study found that the smokers progressed to AIDS in a median time of 8.2 months compared with 14.5 months for the nonsmokers.

In addition, an abstract submitted to a joint meeting of the Association of American Physicians and five other organizations in Washington, D.C. suggests that smoking may increase the load of HIV in the lungs and accelerate the progression to AIDS. ▼

"Sperm Cleaners"

Researchers at the University of Milan Medical School report in "The Lancet" a system to "clean" sperm of HIV. Their study offers hope to HIV discordant couples who want to conceive. Twenty-nine HIV-negative women were inseminated with "cleaned" semen from their HIV-positive partners. HIV is separated from the semen by spinning the semen in a centrifuge. This process spins the fluid and separates it into distinct particles. The uninfected sperm were then incubated, washed, and inseminated into the women. The researchers report that seventeen women became pregnant and ten babies have been followed. All are HIV seronegative and healthy; the oldest child is now three years old. The researchers also report that none of the 29 women became HIV-infected after six months. Eighteen women are confirmed HIV-negative after eighteen months. Despite this report, it should be noted that since 1988, the US Centers for Disease Control has recommended against insemination from HIV-positive men. Additionally, there are reports of women becoming infected after insemination with HIV-infected semen, including one woman who claims to have undergone a procedure similar to that used in Milan. A final note: reports in "The Lancet" are not peer-reviewed and often must be viewed skeptically. ▼